

Traumatic Brain Injury: A Guide for Caregivers of Service Members and Veterans



Caregiver's Companion



"I would just say that this experience has shown all of us that there's hope at every turn. We have found that through the doctors, through case managers, and through our family and friends who have supported us. We found it in the small changes in Tim's abilities.

There has always been that sense of hope, and even at the bleakest moment, there was always something that you could look back on or look forward to that could give you that hope. I wish that every caregiver could see that and hope that they do. I think most of them do. I think most caregivers are just amazingly resilient people themselves, and they thrive off the strength of their wounded warrior."

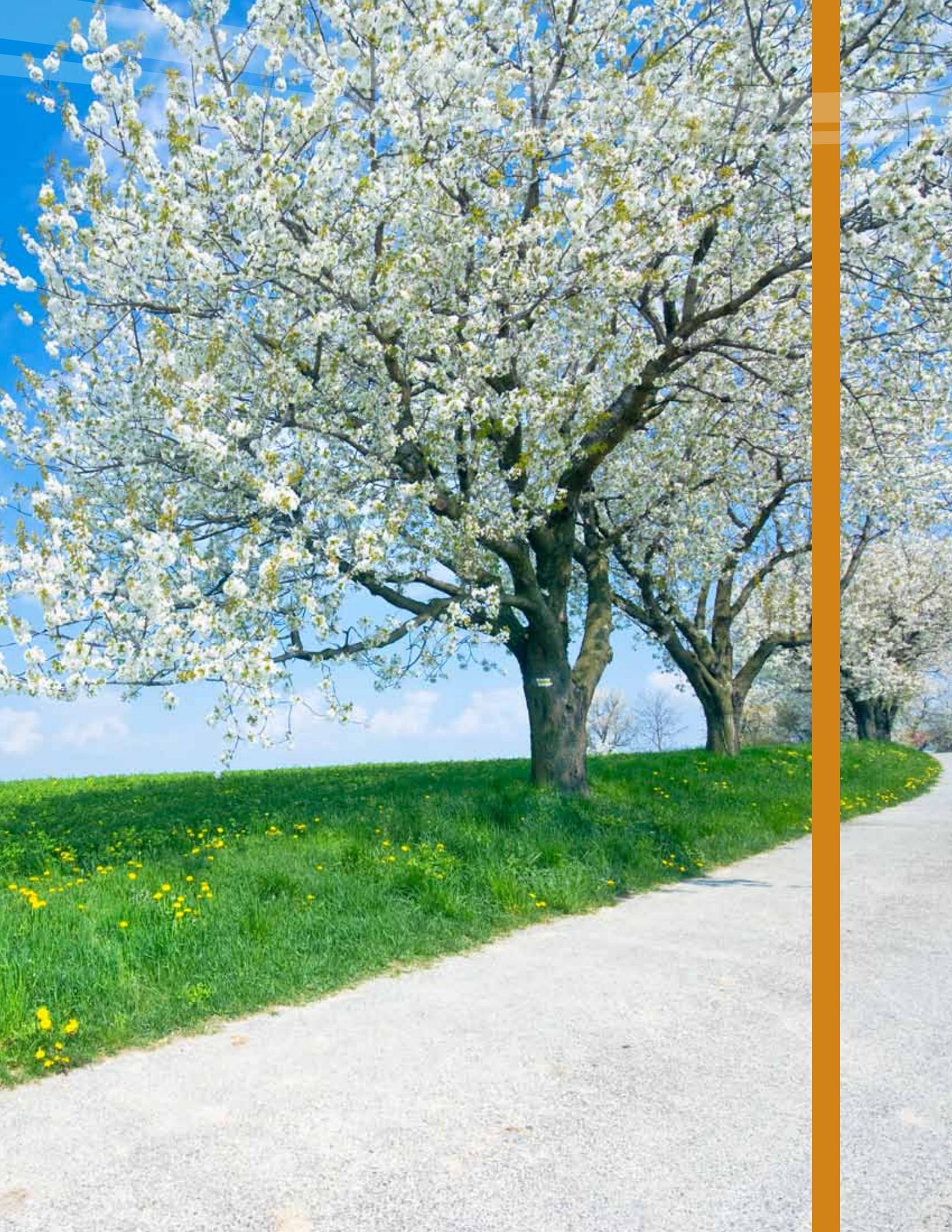
- Shannon M.



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An electronic version of this Guide can be found at the following Web address:
www.traumaticbraininjuryatoz.org





Introduction

This Caregiver's Companion to *Traumatic Brain Injury: A Guide for Caregivers of Service Members and Veterans* has information and forms that can help you in your caregiving journey. Use this binder to keep yourself organized. You may want to carry it with you to keep track of important information. You may need to start a new binder as this one gets full.

The Companion includes:

- A glossary of terms that you're likely to come across time and time again
- A table of military ranks to help you understand the ranks of the service members and officers that you may meet
- A list of acronyms (e.g., DoD for the Department of Defense) to make sense of the alphabet soup within government agencies
- Blank diagrams of the brain that you can use when talking to your health care provider about where the injury occurred
- Master forms to use for writing down key information. The master forms in the Companion are meant to be duplicated. Make several copies of each to use over time or download the forms from www.traumaticbraininjuryatoz.org.

The master forms include:

- contact information for members of the health care team
- medication log to keep track of medications, dosage, timing, and side effects
- home care team volunteer form to keep track of those who volunteer to help
- caregiver support worksheet, to help you list the members of your home care team - the people who can help you take care of all the responsibilities you may not have time for.
- Plastic sleeves to keep business cards of medical professionals and others you want to be able to contact later for more information
- Plastic sleeves for compact disks (CDs) of medical scans and tests you will want to keep. You may need to purchase more plastic sleeves.

May your caregiving journey be one that brings you hope, love, pride, and peace.

Glossary of Medical and TBI Terms

Absence Seizures – A non-convulsive generalized seizure when a person may appear to be staring into space with or without jerking or twitching movements of the eye muscles. These seizures may last for seconds, or even tens of seconds, with full recovery of consciousness and no confusion. People experiencing absence seizures sometimes move from one location to another without any purpose.

Abstract Thinking – Being able to apply abstract concepts to new situations and surroundings.

Acceleration – To increase speed and/or change velocity.

Amnesia – A loss of memory. Amnesia can be caused by brain injury, shock, fatigue, repression, illness, and sometimes anesthesia.

Angiogram – A procedure in which a dye is injected through a thin tube into a blood vessel. Special x-ray pictures are taken, allowing your health care provider to view the blood vessels of the brain, heart, or other part of the body. Also called an arteriogram for arteries or venogram for veins.

Anorexia – A loss of appetite, especially when prolonged over time.

Anosmia – The decrease or loss of the sense of smell.

Anoxia – Absence of oxygen supply to an organ.

Anoxic Brain Injury – Injury to the brain due to severe lack of oxygen. This usually happens when blood is unable to flow to the brain due to certain injuries, bleeding, or cardiac arrest.

Apraxia – The loss or impairment of the ability to perform complex coordinated movements despite having the desire and the physical ability to perform the movements.

Arthralgia – Joint pain or stiffness in a joint.

Ataxia – The inability to coordinate the movement of muscles. Ataxia may affect the fingers, hands, arms, legs, body, speech, or eye movements.

Axons – Also known as nerve fibers, an axon is a long, slender projection of a nerve cell, or neuron, that conducts electrical impulses away from the neuron's cell body or soma. Axons are the primary transmission lines of the nervous system.

Basal Ganglia – The deep brain structures that help start and control voluntary movements and postures.

Blast Injuries – Injuries that result from the complex pressure wave generated by an explosion. The explosion causes an instantaneous rise in



pressure over atmospheric pressure that creates a blast over pressurization wave. Injuries to organs surrounded by fluid, such as the brain, and air-filled organs, such as the ear, lung, and gastrointestinal tract are common.

Brain – The main organ of the central nervous system (CNS). It is divided into the cerebrum, brainstem, and cerebellum. The brain regulates virtually all human activity.

Brainstem – The lower extension of the brain where it connects to the spinal cord. Neurological functions located in the brainstem include those necessary for survival (breathing, heart rate) and for arousal (being awake and alert).

Cerebellum – The portion of the brain (located in the back) that helps coordinate movement.

Cerebral Hypoxia – Inadequate oxygen supply to brain tissue. Mild or moderate cerebral hypoxia is sometimes known as diffuse cerebral hypoxia. It can cause confusion and fainting, but its effects are usually reversible.

Cerebrospinal Fluid (CSF) – A colorless fluid that is found around and inside the brain and spinal cord, offering some protection and cushioning the brain.

Cerebrum – The largest part of the brain. It is divided into two hemispheres, or halves. It controls motor, sensory, and higher mental functions, such as thought, reason, emotion, and memory.

Chronic Subdural Hematoma – An “old” collection of blood and blood breakdown products between the surface of the brain and its outermost covering (the dura).

Closed Head Injury – Injury to structures within the skull or the brain that do not result in an opening in the skull, such as a direct blow to the head or a blast. Injuries may range from a mild concussion to potentially fatal.

Coma – A state of unconsciousness in which the person is not aware of the environment nor able to perform voluntary actions.

Computed Tomography (formerly known as Computerized Axial Tomography) – A painless procedure in which x-rays are passed through the affected area at different angles, detected by a scanner, and analyzed by a computer. CT scan images show bones and blood collections more clearly than conventional x-rays. The computer can combine individual images to produce a three-dimensional view.

Concussion – involves a disruption of brain function caused by trauma. This disruption is characterized by, but not limited to, a loss of consciousness for less than thirty minutes, post-traumatic amnesia lasting for less than 24 hours, and a Glasgow Coma Scale of 13-15. Also referred to as a mild traumatic brain injury.

Consciousness – The state of awareness of the self and the environment.

Contusion – A bruise. In terms of brain injury, a contusion refers to bruising of the brain tissues.

Coup-Contrecoup – An injury to the brain that occurs when an impact or violent motion brings the head to a sudden stop, causing injury to the impact site and the opposite side of the brain. This is also known as an acceleration/deceleration injury.

Cranium – Skull.

Deceleration – To reduce speed or go more slowly.

Diffuse – Widely spread.

Diffuse Axonal Injury, or DAI – Widespread injury of large nerve fibers (axons covered with myelin).

Diffuse Brain Injury – Injury to cells in many areas of the brain rather than in one specific location.

Diplopia – Seeing two images of a single object; double vision.

Dura Mater – The outermost of three membranes protecting the brain and spinal cord. It is tough and leather-like.

Dysarthria – Difficulty in forming words or speaking them because of weakness of the muscles used in speaking. Tongue movements are usually labored and the rate of speaking may be very slow. Voice quality may be abnormal, usually excessively nasal; volume may be weak; drooling may occur.

Dyskinesia – Involuntary movements most often seen in the arms or legs.

Electroencephalograph, or EEG – A test that measures electrical activity of the brain that is recorded from electrodes placed on the scalp.

Epidural Hematoma – Bleeding into the area between the skull and the dura mater.

Euphoria – An exaggerated or abnormal sense of well-being not based on reality.

Executive Functions – The ability to formulate and carry out plans effectively. These functions are essential for independent, creative, and socially constructive behavior.

Expressive Aphasia – Also known as Broca's aphasia. A difficulty in expressing oneself in speech and writing. Characterized by knowing what one wants to say but being unable to find the words to say what is being thought. There is lack of spontaneous speech, words are often labored over, and sentences are short and incomplete.

Focal Brain Injury – Damage confined to a small area of the brain. The focal damage is most often at the point where the head hits an object or where an object, such as a bullet, enters the brain.

Frontal Lobe – The front part of the brain; involved in planning, organizing, problem solving, selective attention, personality, and a variety of "higher cognitive functions."

Generalized Tonic-Clonic Seizures – A seizure involving the entire body. It is also called a grand mal seizure. Such seizures usually involve muscle rigidity, violent muscle contractions, and loss of consciousness.

Glasgow Coma Scale – A scale used for measuring level of consciousness. Scoring is determined by three factors: eye opening ability, verbal responsiveness, and motor responsiveness. The scores range from lowest level of responsiveness (a 3) to highest level of responsiveness (a 15).

Hematoma – A collection of blood caused by the rupture or tearing of blood vessels.

Herniation/Herniated – Compression of brain tissue caused by high pressure inside the skull that can lead to death if not aggressively treated.

Hypertension – The medical term for high blood pressure.

Hypotension – The medical term for low blood pressure.

Hypoxia – Decreased oxygen levels in an organ, such as the brain.

Impaired Initiation – The diminished ability to take the first step in beginning an action.

Improvised Explosive Devices, or IEDs – An IED can be almost anything with any type of material and initiator. It is a "homemade" device that is designed to cause death or injury by using explosives alone or in combination with toxic chemicals, biological toxins, or radiological material. IEDs can be produced in varying sizes, functioning methods,



containers, and delivery methods. IEDs can utilize commercial or military explosives, homemade explosives, or military ordinance and ordinance components.

Intracerebral Hemorrhage – A subtype of intracranial hemorrhage that occurs within the brain tissue itself. Intracerebral hemorrhage can be caused by brain trauma, or it can occur spontaneously in hemorrhagic stroke.

Intracranial Pressure, or ICP – The amount of pressure inside the skull resulting from the brain tissue, cerebrospinal fluid, and blood volume. This pressure normally ranges from 0-10 mm Hg.

Intracranial Pressure (ICP) Monitor – A monitoring device used to determine the pressure within the brain. It is used to assess potential complications resulting from increased pressure exerted on the brain.

Limbic System – A group of structures deep within the brain that are associated with emotion and motivation.

Lobe – A part of the brain located in each of the two hemispheres. Each hemisphere of the cerebrum is divided into four sections known as the frontal lobe, the parietal lobe, the occipital lobe, and the temporal lobe.

Magnetic Resonance Imaging, or MRI – A test that uses a powerful magnet linked to a computer to make detailed pictures of soft tissues inside the body.

Meninges – The covering of the brain that consists of three layers: the dura mater, the arachnoid mater, and the pia mater. The primary function of the meninges and of the cerebrospinal fluid is to protect the central nervous system.

Mild Traumatic Brain Injury, or mTBI – Also referred to as a concussion, mTBI involves a disruption of brain function caused by trauma. This disruption is characterized by, but not limited to, a loss of consciousness for less than thirty minutes, post-traumatic amnesia lasting for less than 24 hours, and a Glasgow Coma Scale of 13-15.

Military Acute Concussion Evaluation, or MACE – A standardized mental status exam that is used to evaluate concussion in theater. This screening tool was developed to evaluate a person with a suspected concussion.

Myalgia – Pain in one or more muscles.

Neurocognitive – Of, relating to, or involving the brain and the ability to think, remember, or process thoughts.

Neuron – A nerve cell that can receive and send information by way of connections with other nerve cells.

Neuropsychology – A science that combines the study of the brain's structures and functions with psychological processes and human behaviors.

Neuroradiological Tests – Tests using computer-assisted brain scans. These tests allow providers to visualize the brain. Tests may include: CT Scan, MRI, Angiogram, EEG, SPECT Scan, PET Scan, DTI Scan.

Neurotransmitters – Chemicals found within the brain that are released from a neuron which transmit signals from neuron to neuron across gaps called synapses. These chemicals either excite or inhibit specific reactions; e.g., in motor neurons, the neurotransmitter causes contraction of muscles through stimulation of muscle fibers.

Nystagmus – Involuntary, usually rapid movement of the eyeballs (side to side or up and down).

Occipital Lobe – The occipital lobe is found at the back of the brain. This lobe receives signals from the eyes, processes those signals, allows people to understand what they are seeing, and influences how people process colors and shapes.

Ocular – Relating to the eye.

Open Head Injury – Trauma to the brain that occurs from a skull fracture or penetrating injury.

Parietal Lobe – The part of the brain that is involved with movement, and with the processing of signals received from other areas of the brain such as vision, hearing, motor, sensory, and memory.

Penetrating Head Injury – A brain injury in which an object pierces the skull and enters the brain tissue.

Perseveration – The repeated and uncontrollable use of the same words or actions regardless of the situation.

Photophobia – An intolerance to light or a painful sensitivity to strong light.

Positron Emission Tomography, or PET Scan – A specialized imaging technique that uses an injection of a short-lived radioactive substance and special CT scans. PET scanning provides information about the body's chemistry not available through other procedures. Unlike other imaging techniques that look at structures of the brain, PET looks at the energy use of different parts of the brain.

Post-Deployment Health Assessment, or PDHA – The military's global health screening that occurs when a unit or service member returns from an overseas deployment. The purpose of this screening is to review each service member's current health, mental health, or psychosocial issues commonly associated with deployments, special medications taken during the deployment, possible deployment-related occupational/environmental exposures, and to discuss deployment-related health concerns.

Post-Deployment Health Reassessment, or PDHRA – A second assessment used 3-6 months following re-deployment or return of service members from overseas deployment. PDHRA extends the continuum of care for deployment-related health concerns and provides education, screening, assessment, and access to care.

Post-Traumatic Amnesia (PTA) – The inability to acquire new memories. For example, a person with TBI may not be able to remember what he or she had for breakfast. Long-term memories, such as those from childhood, are not affected. PTA may range from a period of just a few minutes to a more permanent condition.

Post-Traumatic Stress (PTS) – Anxiety that can develop if you are exposed to or witness a traumatic event (like combat) that threatened or caused great physical harm to self or others.

Rancho Los Amigos Level of Cognitive Functioning – A scale used to follow the recovery of the TBI survivor and to determine when he or she is ready to begin a structured rehabilitation program.

Receptive Aphasia – Also known as Wernicke's aphasia; characterized by difficulty understanding spoken words. Aphasic individuals have difficulty interpreting and categorizing sounds, and speak in what is referred to as a "word salad" with random words put together unintelligibly to form sentences.

Seizure – Uncontrolled electrical activity in the brain, which may produce a physical convulsion, minor physical signs, thought disturbances, or a combination of symptoms. Seizures fall into two main groups. Focal seizures, also called partial seizures, happen in just one part of the brain. Generalized seizures are a result of abnormal activity throughout the brain.



Single-photon Emission Computed Tomography, or SPECT Scan

– Test that uses the injection of a weak radioactive substance into a vein, followed by pictures taken with special cameras. This test is similar to a PET scan and provides information on the energy being used by the brain.

Skull Fracture – A break, split, or crack in the skull.

Subdural Hematoma – Bleeding confined to the area between the outermost covering of the brain (dura) and the brain.

Temporal Lobe – The temporal lobe is located at about ear level, and is the main memory center of the brain, contributing to both long-term and short-term memories. The temporal lobe is also involved with understanding what is heard and with the ability to speak. An area on the right side is involved in visual memory and helps people recognize objects and faces. An area on the left side is involved in verbal memory and helps people remember and understand language. The back area of the temporal lobe helps people interpret the emotions and reactions of others.

Thalamus – A part of the brain that is primarily responsible for relaying sensory information from other parts of the brain to the cerebral cortex.

Tinnitus – “Ringing in the ears” or another noise that seems to originate in the ears or head.

Traumatic Brain Injury, or TBI – An injury to the brain as the result of trauma to the head.

Whiplash – An injury to the neck caused when the head is violently thrown back and forth, such as in a rear end car collision.

U.S. Military Ranks

Pay Scale	Army	Air Force	Marines	Navy and Coast Guard
Enlisted Personnel				
Special E-9	Sergeant Major of the Army 	Chief Master Sergeant of the Air Force 	Sergeant Major of the Marine Corps 	Master Chief Petty Officer of the Navy 
E-9	Command Sergeant Major  Sergeant Major 	First Sergeant (Chief Master Sergeant)  Chief Master Sergeant 	Sergeant Major  Master Gunnery Sergeant 	Command Master Chief Petty Officer  Master Chief Petty Officer 
E-8	First Sergeant  Master Sergeant 	First Sergeant (Senior Master Sergeant)  Senior Master Sergeant 	First Sergeant  Master Sergeant 	Senior Chief Petty Officer 
E-7	Sergeant First Class 	First Sergeant (Master Sergeant)  Master Sergeant 	Gunnery Sergeant 	Chief Petty Officer 
E-6	Staff Sergeant 	Technical Sergeant 	Staff Sergeant 	Petty Officer First Class 

Pay Scale	Army	Air Force	Marines	Navy and Coast Guard
Enlisted Personnel				
E-5	Sergeant 	Staff Sergeant 	Sergeant 	Petty Officer Second Class 
E-4	Corporal  Specialist 	Senior Airman 	Corporal 	Petty Officer Third Class 
E-3	Private First Class 	Airman First Class 	Lance Corporal 	Seaman 
E-2	Private 	Airman 	Private First Class 	Seaman Apprentice 
E-1	Private (Recruit)	Airman Basic	Private	Seaman Recruit

Commissioned Officers

Special**	General of the Army 	General of the Air Force 		Fleet Admiral 
O-10	General 	General 	General 	Admiral 

Blank indicates there is no rank at that pay grade.

** Ranks used infrequently, during wartime.

U.S. Military Ranks

Pay Scale	Army	Air Force	Marines	Navy and Coast Guard
Commissioned Officers				
O-9	Lieutenant General ★☆☆☆	Lieutenant General ★☆☆☆	Lieutenant General ★☆☆☆	Vice Admiral ★☆☆☆
O-8	Major General ★☆☆	Major General ★☆☆	Major General ★☆☆	Rear Admiral (Upper Half) ★☆☆
O-7	Brigadier General ★	Brigadier General ★	Brigadier General ★	Rear Admiral (Lower Half) ★
O-6	Colonel 	Colonel 	Colonel 	Captain
O-5	Lieutenant Colonel 	Lieutenant Colonel 	Lieutenant Colonel 	Commander
O-4	Major 	Major 	Major 	Lieutenant Commander
O-3	Captain 	Captain 	Captain 	Lieutenant
O-2	1st Lieutenant 	1st Lieutenant 	1st Lieutenant 	Lieutenant, Junior Grade
O-1	2nd Lieutenant 	2nd Lieutenant 	2nd Lieutenant 	Ensign

Pay Scale	Army	Air Force	Marines	Navy and Coast Guard
Warrant Officers				
W-5	Chief Warrant Officer 5 		Chief Warrant Officer 5 	Chief Warrant Officer 5 
W-4	Chief Warrant Officer 4 		Chief Warrant Officer 4 	Chief Warrant Officer 4 
W-3	Chief Warrant Officer 3 		Chief Warrant Officer 3 	Chief Warrant Officer 3 
W-2	Chief Warrant Officer 2 		Chief Warrant Officer 2 	Chief Warrant Officer 2 
W-1	Warrant Officer 1 		Warrant Officer 1 	Warrant Officer 1 

Military Terms

Here are terms that you may hear when you are on a military base or military hospital.

Terms related to injuries and treatment:

- BI – Battlefield Injury
- CASEVAC – Casualty Evacuation
- MTF – Medical Treatment Facility; for example:
 - NNMC – National Naval Medical Center, commonly called "Bethesda"
 - NMCSD – Naval Medical Center San Diego, commonly called "Balboa"
 - BAMC – Brooke Army Medical Center
 - WRAMC – Walter Reed Army Medical Center
- OT – Occupational Therapy
- PT – Physical Therapy
- PTSD – Post-Traumatic Stress Disorder
- SCI – Spinal Cord Injury
- TBI – Traumatic Brain Injury
- VSI, SI, SPECAT – Very Seriously Injured, Seriously Injured, Special Category
- WII – Wounded, Ill, and Injured

Terms related to Medical Review Boards:

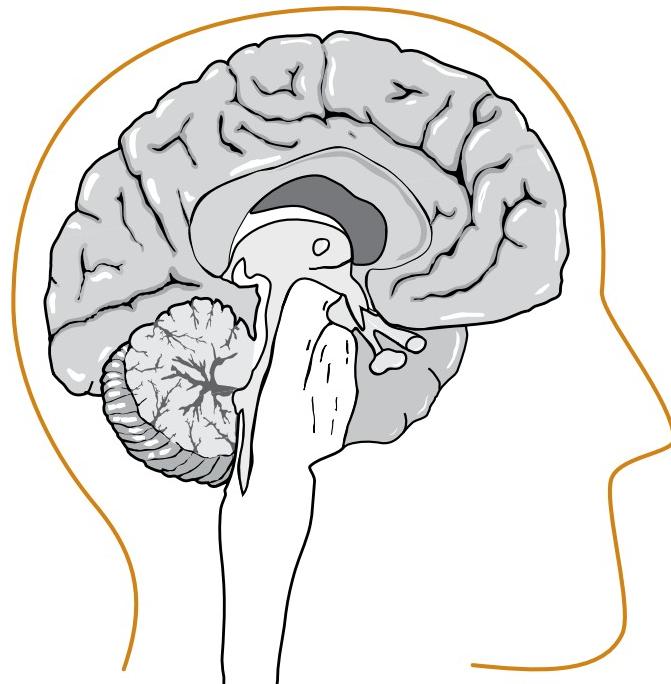
- COAD – Continuation on Active Duty
- COAR – Continuation on Active Reserve
- DES – Disability Evaluation System
- EPTE – Existed Prior to Entry
- HAO – Home Awaiting Orders
- MEB – Medical Evaluation Board
- MMRB – MOS Medical Retention Board
- MOS – Medical Occupational Specialty
- PEB – Physical Evaluation Board
- PDRL – Permanent Disability Retirement List
- PLD – Permanent Limited Duty
- TDRL – Temporary Disability Retirement List
- VASRD – Veterans Affairs Schedule for Rating Disabilities

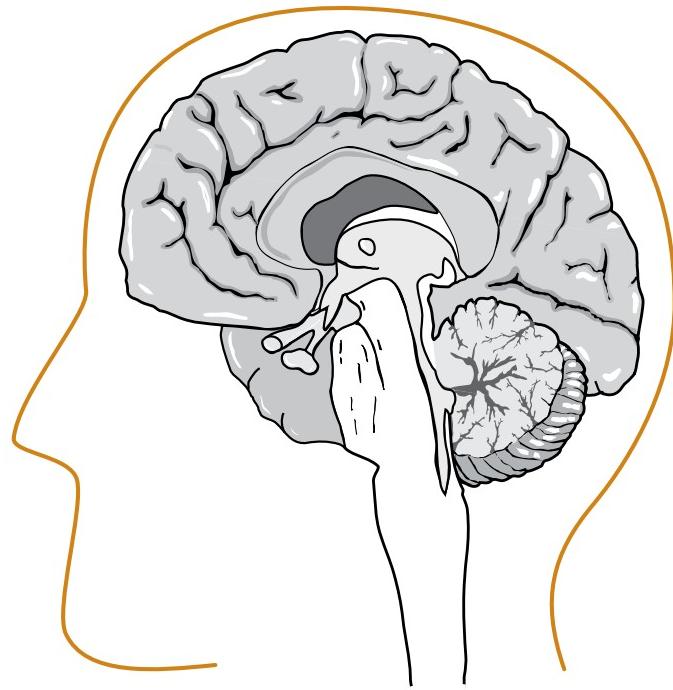
Other terms:

- AW2 – U.S. Army Wounded Warrior Program, formerly called DS3
- BAH – Basic Allowance for Housing
- BAS – Basic Allowance for Subsistence
- CACO – Casualty Assistance Call Officer
- CONUS – Continental U.S. (OCONUS is Outside the Continental U.S.)
- DoD – Department of Defense
- FMLA – Family and Medical Leave Act
- IED – Improvised Explosive Device
- ITOs – Invitational Travel Orders
- M4L – Marine For Life
- MLO – Marine Liaison Office
- NMA – Non-Medical Attendant
- OEF – Operation Enduring Freedom
- OIF – Operation Iraqi Freedom
- PNOK – Primary Next of Kin
- SSN – Social Security Number
- TSGLI – Traumatic Servicemembers' Group Life Insurance
- VA – Department of Veterans Affairs
(formerly called Veterans Administration)
- VBA – Veterans Benefits Administration
- VSO – Veteran Service Officer

Diagrams of the Brain

These drawings of the brain may be used by the health care team to show you the area of injury in your service member/veteran.





Contact Information of the Health Care Team Members

PROFESSIONAL - NAME	CONTACT INFORMATION
Audiologist	
Cardiologist	
Case Manager(s)	
Chaplain Services	
Department of Defense Military Liaison	
MEB/PEB Case Manager	
Neurologist	
Neuropsychologist	
Neurosurgery Specialist	
Nurse	
Occupational Therapist (OT)	
Ophthalmologist	
Optometrist	

Contact Information of the Health Care Team Members

PROFESSIONAL - NAME	CONTACT INFORMATION
Orthopedic Specialist	
Physiatrist (Physical Medicine and Rehabilitation Specialist)	
Physical Therapist (PT)	
Plastic Surgeon	
Primary Care Provider	
Recreational Therapist	
Registered Dietitian	
Rehabilitation Nurse	
Rehabilitation Psychologist	
Speech/Language Pathologist	
Social Worker	
Urologist	

Contact Information of the Health Care Team Members

PROFESSIONAL - NAME	CONTACT INFORMATION



Medication Log

Medication Log

Caregiver Support Worksheet

Caregiving Task	Who Can Help	Contact Information
Everyday Tasks:		
Meal Planning		
Lawn Care		
Grocery Shopping		
Meal Preparation		
Light Housekeeping		
Transportation for:		
Other Family Members		
Shopping & Errands		
Child Care		
Pet Care		
Care Tasks:		
Coordinating Home Care Team		
In-home Supervision/Companionship		
Transportation for:		
Medical Appointments		
Support Group/Counseling		
Care Team Meetings/Dinner		
Personal Hygiene:		
Bathing		
Other, e.g. hair, nails, skin		
Hands-on Medical Treatments/Exercise/Therapy		
Scheduling Medical Appointments		
Managing Medications		

Caregiver Support Worksheet



Home Care Team Volunteer Form







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and
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